ILLNESS BEHAVIORS OF THE PATIENT WITH CHRONIC HEADACHES

by

Helen Elaine Eschenbacher

A thesis submitted to the faculty of
The University of Utah
in partial fulfillment of the requirements for the degree of

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College of Nursing

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THE UNIVERSITY OF UTAH GRADUATE SCHOOL

SUPERVISORY COMMITTEE APPROVAL

of a thesis submitted by

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ABSTRACT

Personal beliefs, illness behaviors, and present expectations were identified in a group of 43 chronic headache patients. History taking mirroring a patient explanatory model was used for the interview. These patients had minimal insight into mechanisms and trigger factors of headaches. Headaches were seen as a separate entity not under the patient's locus of control. Headaches were not identified by the patients as being a behavioral pattern. Few self-directed interventions were noted. Non-M.D. practitioners, such as chiropracters, osteopaths, and herbalists were commonly consulted. In the formal health care system, neurologists and other physicians were consulted extensively. Expectations of diagnosis, treatment and follow-up care was widely divergent between medical practitioners and patients. Dissatisfaction with the health care system was high, as reported by this group of chronic headache patients.

If a man does not keep pace with his companions, perhaps it is because he hears a different drummer. Let him step to the music which he hears, however measured or far away.

-Henry David Thoreau

CONTENTS

LIST OF TABLES

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CHAPTER I

INTRODUCTION

"If I wanted to show a student the difficulties of medical practice, I should give him a headache to treat" (Moench, 1947, p. 3). This statement by Oliver Wendell Holmes remains true in the practice of health care today. The purpose of this study was to identify the illness behaviors of patients with chronic headaches, thus giving the health practitioner more information about the patient and the illness.

Headache has been called the most common medical complaint of civilized man. Eighty to ninety percent of the adult population will experience significant headache pain at least once in a lifetime that will require intervention (Conway-Rutkowski, 1981). For some, the headache is transient and never interferes with the normal activities of daily living. However, this problem can be more pervasive and chronic. In 1976 and 1977, 1.7% of all visits to primary care practitioners were for the primary problem of headaches, totalling ten million visits per year. Medical

attention was sought by 2.7 million people with headaches. Activity restriction totalled 5.5 million days (National Center for Health Statistics, 1982). Moreover, headaches constitute one of the significant complaints in more than 50% of all patients seen in office practice (Friedman, 1959).

The most medically common headaches are those associated with mood disorders, particularly depression, anxiety, and emotional tension. "Severe, recurring chronic headaches are only infrequently caused by organic disease" (Dalessio, 1980, p. 13). Chronic headaches represent an inability of an individual to cope in some measure with the uncertainties of life; it is a symptom of an underlying disorder of thought or behavior rather than structural disease of the nervous system (Dalessio, 1980). Demjen and Bakal (1981) stated that illness behavior may play a direct role in the development and maintenance of chronic headaches.

Chronic headaches usually influence a person's affect, causing irritable, depressed, aggressive and hostile behavior. Memory, particularly short-term memory, is also altered, resulting in impaired learning ability and diminished self-confidence. Headaches reduce working capacity and affect the person's behavior toward his family, work cohorts, and society.

Numerous headache sufferers often fall victim to intolerance and hostility from relatives, schoolmates or colleagues. Physicians, nurses and the general public all have negative stereotypes of the patient with chronic headaches as compared with patients with other chronic illnesses (Frank, 1977). Even significantly lower self-concepts were obtained from headache patients themselves as compared with the self-concepts of other types of medical patients (Armentrout, 1979). These differences were believed to come from the loss of many normal functions and disruption of lifestyle by the headache patient. The patient eliminates potentially pleasurable activities from families and friends (Cinciripin & Floreen, 1982). Chronic headaches change behaviors and illness behaviors then maintain chronic headaches; the circle is then complete.

Even though headaches are usually nonstructural and nonorganic, the medical model persists in categorizing types of headaches, ad infinitum. Headache classification has evolved because there are no objective findings which define headache types. The resultant groupings are inconsistently defined, and are probably not optimal for the study or treatment of headache patients (Diehr, 1982). Because a current medical history is based on this classification style,

enough thorough information is not being elicited for effective assessment and treatment.

Contemporary medical practice has become increasingly discordant with lay expectations. In a perspective of anthropological and crosscultural research (Kleinman, Eisenberg & Good, 1978), a dichotomy of "disease/illness" was discussed. Modern physicians diagnose and treat diseases. Kleinman's definition of disease is an abnormality in the structure and function of body organs and systems. In addition to disease, patients also suffer illnesses. Illness is defined as experiences of disvalued changes in states of being and in social function -- the human experience of sickness. Illness may often occur in the absence of a disease, such as a headache.

> Moreover, even "correct remedies" prescribed for the appropriate disease may fail, despite effective pharmacologic action, when patients fail to continue the medical regimen, because they do not understand or agree with the physician's rational for the regimen (Kleinman et al., 1978, p. 253).

Biomedicine is primarily interested in the recognition and curing of diseases. This medical approach has been ineffective in treating the chronic illness of headache.

In an effort to develop a more complete data base for evaluation of illnesses, Kleinman et al. (1978) suggested use of a "patient explanatory model" in place

of the "usual medical history." This model elicits health beliefs in addition to a more extensive patient history. The patient is thus approached with better understanding of his beliefs and expectations associated with the illness. This allows the development of a treatment plan that would fit the patient's specific mode of thinking and behavior.

This study also looks at the self-interventions used by patients with chronic headaches. Seventy to ninety percent of all self-recognized episodes of illness, such as headaches, are managed exclusively outside the perimeter of the formal health care system (Dalessio, 1980). More information is needed regarding self-therapy and decision making in the popular health care sector.

Purpose of the Study

The purpose of this study was to identify illness behaviors, illness perceptions, and self-interventions of patients with chronic headaches.

Significance of the Study

More thorough understanding of the individual patient's previous interventions, illness behaviors and illness perceptions provides the health practitioner with the means to construct specific management

protocols for each patient. The current medical model has had limited success in the management of chronic headaches. In learning to manage the chronic illness of recurrent headaches, a more comprehensive health history, including beliefs and behaviors must be incorporated into the medical model.

CHAPTER II

REVIEW OF THE LITERATURE

Headache is one of the most universal of all symptoms. The earliest descriptions of headache and "sick headache" go back some 5000 years. Hippocrates described what we now call the migraine syndrome as having periodic headache with visual disturbances and vomiting. Other early writers such as Cornelius Celsus, Aretaeus, and Galen added to this information (Critchley, 1967). But the history of headache predates recorded time. Small holes found drilled in the skulls of prehistoric human remains may well have represented attempts at relieving pain (Saper, 1981).

Chronic headaches were suffered by such individuals as Cervantes, Thomas Jefferson, Sigmund Freud, Ulysses S. Grant, Karl Marx, Julius Caeser, Leo Tolstoy, Virginia Woolf, Edgar Allan Poe, Tchaikovsy, Chopin, Charles Darwin, and George Bernard Shaw. Lewis Carroll, author of Alice's Adventures in Wonderland, also suffered headaches. Through the character of Tweedledum, Carroll states, "I'm very brave, generally, only today I happen to have a headache."

> If one should search for the human ill which has manifested itself most widely during all times and among all people, there can be but little doubt that headache would attain that unenviable distinction (Moench, 1947, p. 18).

> Head pain is not like other pain. A headache occurs at the center of the mind; it affects the captain of the ship and disrupts the control center of the body. Headaches do not simply strike at your muscles or organs, they attack the very essence of you. Marital discord, depression, fear, isolation, drug abuse, a feeling of helplessness, and even suicide are only a few of the consequences characterizing a headache-possessed existence (Saper, 1981, p. 38).

Headache is a complaint of nearly half of all patients who see a primary care practitioner (Friedman, 1981). It has been estimated that 90% of all people living in the United States have suffered from headache at one time or another. Only about 10% seek specific treatment for their headache. The loss of function and productivity can assume vast proportions.

Headache is a symptom that may be indicative of any intracranial or systemic disturbance, a personality or situational problem, or combination of these factors.

> It is, in itself, not a disease. It is a symptom, which may occur in a host of disease entities, or it may be part of a "migraine syndrome" of which headache is usually the characteristic sign (Friedman, 1981, p. 89).

The complexity and frequency of headaches constitute a medical problem of no little magnitude.

> Its diagnosis and treatment are neither simple nor commonplace. To the patient, headache is a

> disease, but to the physician, it is only a symptom, a symptom of an illness which may be either organic or functional (Atkinson & Appendzeiller, 1982, p. 28).

Patient Classification Using the Medical Model

Even though the classification system is felt by some to be outmoded, general categories will be outlined here and will be used in reference to the medical model part of the patient history.

The medical community via clinical observation of subjective symptomatology has classified headaches. In 1962, an Ad Hoc Committee of the National Institute of Neurological Diseases and Blindness published this classification.

The most common chronic headaches can be divided into two categories: a) vascular headaches of the migraine type, and b) nonvascular headaches -- mainly "muscle-contraction" or "tension" headaches.

Definition of Vascular Headaches

Vascular headaches of the migraine type are described as recurrent attacks of head pain, widely varied in intensity, frequency and duration. The attacks are commonly unilateral in onset (though this is now in dispute) (Diehr, 1982), are usually associated with anorexia, sometimes nausea and vomiting. In some

patients, headaches are preceded by, or are associated with, conspicuous sensory, motor or mood disturbances; these headaches are often familial. These vascular migraines are then further categorized as classic, common, or complicated. Migraines may be defined according to the affected vascular system; for example, retinal migraine, opthalmic migraine, or basilar artery migraine.

Classic migraine refers to a syndrome involving paroxysms of headache with sharply defined auras that precede the headache. These auras last only a few minutes and directly precede the headache pain. At times, the syndrome only exhibits the aura and never proceeds into the headache phase. The aura may be disturbances of sensation (usually visual scotomata or limb and facial paresthesias), motor dysfunctions (such as dysarthria or limb paralysis) or marked mood disturbances. Common migraine headaches are not associated with an aura.

Another part of the migraine syndrome reported in the literatuere is the prodrome. Migraine prodromes may be noted hours or days before the rest of the migraine complex. Described as having "insidious onset," these prodromes usually last a few hours and affect mood, behavior, wakefulness, gut motility, and/or fluid

balance. These prodromes have been reported with both classic and common migraines. These prodromal symptoms have been described as "feeling dangerously well before an attack," "an irresistible and horrid drowsiness," "having a greedy appetite," or "being capable of taking on the world" (Atkinson, 1982).

Complicated migraine is associated with transient (or, in exceptional cases, permanent) symptoms of excitation and/or deficit of sensory or motor functions. Complicated migraines encompass migraine subtypes such as opthalmoplegic or hemiplegic migraines.

The aura and prodrome of the migraine syndrome is thought to be due to vasoconstriction of cranial arteries secondary to a trigger factor on unstable vessels. This is then thought to decrease cerebral blood flow to certain areas of the brain resulting in disturbances felt and seen. The unstable arteries then dilate and distend causing head pain. The pathophysiology of this instability is not well established. Neural and humoral controls, platelet changes and vasoactive substances all appear to be involved in the mechanism of the migraine (Diamond & Medina, 1981).

The duration of the headache may be from a few hours to four or five days. The headache is episodic as

contrasted to a headache that lasts for days, weeks or months. Onset of migraines generally develops between the ages of 5 and 35 years. The pain of migraines is often present in the morning, but may come on at any time of the day or night and may awaken the patient from sleep. Pain is often dull and steady, but may become pulsatile when severe (Atkinson, 1982). Other authors such as Friedman (1981) and Wolff (Dalessio, 1980) only describe the pain as throbbing.

Multiple trigger factors in migraine headaches have been suggested including stress, hypoglycemia, and dietary constituents (Atkinson, 1982). However, in a recent study, the conclusion was also drawn that "at this point in research, exposure to brief laboratory stress was not sufficient to produce headache in headache-prone patients" (Feuerstein, Bush & Corbisiero, 1982, p. 172). Rather than one specific triggering factor, a cumulative effect of several or many factors is probably necessary to trigger a migraine.

Current Treatment of Vascular Headaches

Treatment has been aimed at use of ergot preparations during the vasoconstrictive phase of the migraine complex. This phase can only be identified if a sharply defined aura is present. Use of analgesics

during the phase of headache pain or use of vasoactive drugs between migraine headaches are also common modes of treatment. The vasoactive drugs -- such as "beta blockers," are thought to stabilize the cranial arteries preventing the stages of vasoconstriction and distention.

But the treatment may contain hazards. Use of ergot compounds may result in rebound headaches, gangrene of extremities, and retroperitoneal fibrosis (Diamond, 1981). Use of prescribed or over-the-counter analgesics may result in a syndrome known as "analgesic-associated nephropathy" and consequent renal failure (Murray & Goldberg, 1978). Even the vasoactive drugs have recently been implicated in the possible cause of completed strokes and/or complicated migraines in patients with classic migraines (Atkinson, 1982).

Elimination or control of trigger factors has also been attempted with varying degrees of success. Much has been written trying to identify multiple trigger factors. In rare cases, one main causative agent -- such as red wine -- can be isolated and eliminated from the individual's diet with resultant decrease of headaches. But for the most part, the trigger factors may be multiple or so obscure as to never be identified. Also, many authors do not believe that easily

identifiable factors even exist at all (Atkinson, 1982).

Definition of Nonvascular Headaches

The main group of nonvascular headaches are the "muscle-contraction" or "tension" headaches. These headaches are characterized by mild to moderate nonthrobbing pain (also described as "tightness" or "pressure") involving the head and neck, unassociated with autonomic disturbances. There is a marked association with stress, anxiety or depression. Patients with chronic tension headaches complain of a specific and continuous headache. "Thirty percent of these patients have at least one headache a day. Twenty percent describe constant pain. These patients almost always report a sleep disturbance" (Dalessio, 1981, p. 98). The headache obtains its name from the fact that it usually is associated with sustained contraction of the skeletal muscles of the neck and head or general muscle tension.

Emotional factors appear to be of prime significance in the genesis of muscle contraction headache. Multiple conflicts are usually evident. One hypothesis of pathogensis is that stressful events probably produce a biochemical change in the brain

giving rise to a more or less manifest depression. Levels of endorphins are reduced leaving the patient susceptible to chronic pain. The localization of the pain to the head could be explained by:

1. The predisposition to migraine headache found frequently in those patients, or

2. The presence of local trigger factors such as cervical osteoarthritis or temporal mandibular joint dysfunction (Diamond, 1981).

This idea of pain generation in chronic pain syndromes is being investigated in fibromyalgia or fibrositis, a seemingly close corollary of muscle contraction headaches (Polley & Hunder, 1978). The end result is the noted reaction of the muscles and blood vessels. The muscles become tonically contracted and the vessels constrict, causing an ischemic type of muscle pain with local tenderness.

The term muscle contraction headache is a misnomer in that it is a symptom of this headache syndrome, not the cause. For example, it is possible to reproduce the peripheral phenomena without producing the headache. People who habitually frown, clench their teeth, or experience anxiety commonly exhibit contraction of the head and neck muscles but only a few may complain of headache. Likewise, vigorous physical exercise or a hot

bath produce arterial vasodilation, but again only rarely does migraine headache occur in a nonheadache prone patient (Diamond, 1981). Overall, chronic muscle contraction headaches are the most common type of all chronic headaches.

Current Approaches to Treatment of Muscle Contraction Headaches

Treatment for muscle contraction headaches has mainly been aimed at controlling the psychogenic factors usually associated with this type of chronic headache. Counseling and/or psychiatric referral is used to identify any underlying conflicts or disorders of thought. Drug treatment has been twofold: a) to correct possible underlying biochemical alterations, by using amitryptilline and other antidepressants, and b) to abort the pain cycle with short-term use of nonsteroidal, anti-inflammatories and/or narcotic analgesics. Before initiating any type of drug treatment, all other drugs should be stopped for at least two weeks (Kudrow, 1982). Biofeedback is becoming a significant instrument in the multivaried approach to controlling muscle-contraction headaches. It is usually used in association with drug therapy and/or counseling.

Concept of Mixed-Headache Syndrome

Until recently, migraine and muscle contraction headaches have been considered distinct entities. Current thinking is that these headaches may coexist during a particular headache occurrence or occur independently along a continuum of clinical expression (Saper, 1982). The patient is diagnosed with "mixed headache syndrome." The syndrome, by definition alone, is more nebulous and thus becomes more difficult to treat. Treatment is aimed at combining therapies previously used for vascular and muscle-contraction headaches. Effective combinations dealing with both the vascular and nonvascular components of this new entity remain an art form at this stage.

Health Practitioner Intervention

No matter what the technical diagnosis, it is important to think of headaches as chronic illnesses. Cure is probably not a viable objective because the headache is only a symptom and the pathogenesis is not well understood. The syndrome could be controlled.

Individuals with chronic headaches may be biologically predisposed to excessive physiologic reactivity to internal and external stimuli (Saper, 1983). The biological predisposition, at this time,

cannot be changed, but treatment can be aimed at stabilizing the excessive reactivity or seeking control over the external and internal stimuli. The behaviors of the patients, therefore, must be taken into account when developing treatment.

A working relationship between the health practitioner and patient is the basis for all treatment. Saper (1981) stated that there must be an establishment of a trusting relationship between practitioner and patient. The practitioner must convey genuine interest in the patient's distress and provide ample time for the exchange of information and for patient concerns. There must be a development of open communication regarding all aspects of the patient's life since headache frequently represents the somatic expression of a patient's distress. Suchman (1970) listed four concepts for more intelligent intervention by the practitioner. The practitioner should have knowledge and awareness of: a) the patient's views of health, b) the patient's sickness, c) the patient's expectations, and d) the patient's reasons for seeking help. Diamond (1981) stated the treatment of tension headache should involve several appointments. This allows time for the patient to gain confidence in the practitioner and helps the practitioner identify the cause of the headache and

begin a treatment plan. This concept of multiple appointments is not included in the treatment plan of vascular headaches by the same author.

Recently, a multidisciplinary approach has been used to treat chronic headaches. "Pain clinics," comprised of psychiatrists, psychologists, physical therapists and others work with the patient for a number of weeks on an inpatient basis. Behavioral modification and strictly controlled use of analgesics are standard therapy. Biofeedback and hypnosis are additional forms of therapy. These latter two modalities are used in outpatient care also. This approach was developed for the treatment of chronic muscle contraction headaches but behavioral therapies are entering the treatment phase of vascular headaches.

Cinciripini (1982) cited that the results of behaviorally oriented pain programs are very promising given the rather "poor" success rate of traditional intervention" (p. 382). Cinciripini described programs using exercise, biofeedback/relaxation training, behavioral group therapy with videotaping, short-term and long-term goal contracts, self-monitoring, family training and follow-up.

Ditomasso and Colameco (1982) discussed patient self-monitoring of behavior. Since practitioners often

rely solely on patient's recollections of events in the assessment and treatment of psychosomatic complaints, reliable data is necessary. To improve the data, the patient should systematically collect and summarize his complaints. This is done by having the patient monitor his own behavior in diary form or on a daily calendar. The following is then accomplished: a) the problem is seen in its natural environment, b) the patient assumes a more active role in treatment, c) the patient discerns finer discrimination about his behavior, d) the patient makes beginning evaluations of possible trigger factors or causes for headaches, and e) the patient will gain insight into behaviors that may cause his headache profile. Behavioral therapy is becoming a major part of the treatment of chronic headaches in the current realm of medical therapy.

CHAPTER III

CONCEPTUAL FRAMEWORK

> Illness is the culturally constituted, socially learned response to symptoms that includes the way we perceive, think about, express, and cope with sickness. When the sick person first visits a practitioner, the two initially communicate in terms of culturally shared illness idioms. [The practitioner] begins to further construct the sickness in the technical terms of his theoretical system, be it biomedicine, psychoanalysis, chiropractic or traditional Chinese medicine (Kleinman, 1982, p. 119).

This technical reconstruction constitutes disease.

This concept of disease/illness was first expressed in the perspective "Culture, Illness and Care" (Kleinman, 1978). This disease/illness concept was seen as a dichotomy and a major problem in health care today. For patients, illness problems -- the difficulties in living resulting from sickness -- are usually viewed as constituting the entire disorder. Conversely, practitioners often disregard illness problems because disease is looked upon as the only disorder (Zola, 1972). Disease is defined as an abnormality in the structure or function of body organs and systems. Both views are insufficient in themselves.

In this paper, "disease has been defined as a

medically structural or functional abnormality. This seems to perpetuate the idea of dichotomy of illness versus disease. However, it should be remembered that the word disease means precisely that -- "dis-ease" and should be thought of in the same mode as illness. For the sake of this paper, disease is defined in a smaller, more specific, way in discussing the illness/disease dichotomy used as part of the underlying conceptual framework.

Biomedicine is primarily interested in recognition and treatment of disease. It is interested in the elimination of disease and in curing. "So paramount is this orientation that the professional training of doctors tends to disregard illness and its treatment" (Kleinman, 1978, p. 253). Biomedicine has increasingly banished the illness experience as a legitimate object of clinical concern. "Carried to its extreme, this orientation, so successful in generating technological interventions, leads to a veterinary practice of medicine" (Kleinman, 1978, p. 253). On the other hand, lay people and folk practitioners, such as herbalists and chiropracters, may treat illness effectively, but diseases are not systematically recognized and treated. If both the patient's perspective of his illness and the disease process are viewed together, better management of

the sickness is possible. Only modern health professionals are potentially capable of treating both disease and illness. Clinical science must be thought of in terms of both biomedical and social science. There must be a strategy for applying social science concepts to the current medical model.

The current medical model for history-taking includes etiology, onset of symptoms, pathophysiology, course of illness, and treatment. In Kleinman's perspective (1978), a different model for history-taking is the patient-explanatory model. This model reflects social class, cultural beliefs, education, occupation, religious affiliation and past experiences with illness and health care (Kleinman, 1975). This model will provide the practitioner with knowledge of the beliefs surrounding the illness, personal and social meaning attached to the illness, expectations of therapeutic intervention and course of illness, and the patient's own therapeutic goals.

Comparing the patient model with the medical model enables the clinician to identify major discrepancies that may cause problems in management. Comparisons also help the clinician determine appropriate patient education. Different values and interests become the area of conflict rather than different levels of

knowledge being the problem. The clinical process will then involve negotiation between the models. Kleinman (1978) outlined a common set of questions that could be adapted to elicit the patient explanatory model (Appendix A). The questions require subjective, individualized answers and will reflect beliefs and perspectives held by the patient about the illness.

In addition to a list of disease problems, a list of illness problems should then be recorded. Illness interventions, primarily psychosocial in nature, should be formulated and applied along with disease interventions. Then through negotiation and education ways can be sought to ameliorate both sets of problems, thus achieving goals for both patient and practitioner.

> This approach may obviate the need to consult psychiatrists, social workers, and psychologists who presently function as surrogates for the diagnosis and treatment of illness problems (Kleinman, 1978, p. 257).

To achieve better assessment, management, and treatment of chronic illness, the patient's perspective and beliefs must be taken into account. The patient's goals, along with the practitioner's goals, must be integrated into a plan using comparison, negotiation and education.

Conceptual Definitions

The following definitions were employed in the course of this investigation (see Figure 1).

Illness

Illness was defined as the experience of disvalued changes in state of being and in social function, the human experience of sickness (Engel, 1977). Illness is an abnormal biological affliction or mental disorder with a cause, characteristic, or train of symptoms that has a method of treatment (Cockerham, 1978). Illness represents personal, interpersonal, and cultural reactions to disease or discomfort. It is culturally constructed (Kleinman, 1977).

Illness Behavior

Illness behavior was defined by Kasl and Cobb (1966) as the activity undertaken by a person who feels ill, for the purpose of defining that illness and seeking relief from it. We learn "approved ways" of being ill.

Disease

Disease was defined as an abnormality in the structure and function of body organs and systems (Engell, 1977). In the nineteenth century, research led to the conceptualization of the germ theory of disease.

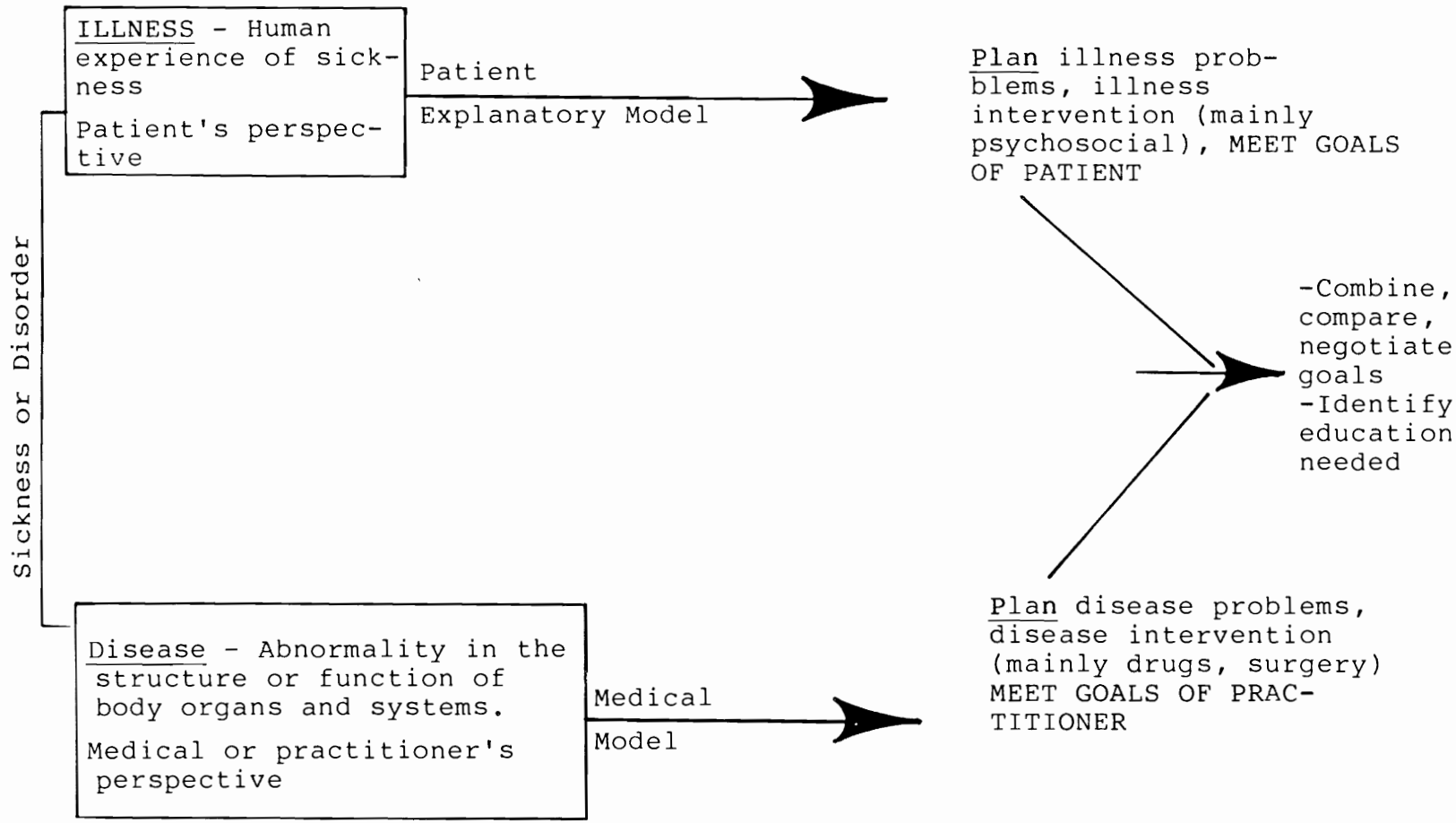

Figure 1. Diagram of conceptual definitions of illness/disease dichotomy.

The practice of medicine in the twentieth century thus rested solidly upon the premise that every disease had a specific pathogenic cause whose treatment could be best accomplished by removing or controlling that cause within a biomedical framework (Cockerham, 1978).

Chronic Headache Syndrome

In this investigation, chronic headache syndrome was defined as a permanent health disorder. It manifests itself by long-standing, recurrent headaches as opposed to temporary, acute headaches. The syndrome seems to be of a mainly functional basis, not in association with organic disease.

Patient Explanatory Model

The patient explanatory model was defined as a collection of the cultural, sociological, psychological and biological makeup of the patient and his illness behaviors.

Research Questions

Using the conceptual framework of the patient explanatory model (Kleinman, 1978), the patient's perspective of illness will be reflected. A factor-seeking level of inquiry will involve the following research questions:

1. What is the nature of the chronic headaches?

2. What are the personal beliefs these patients hold about chronic headaches?

3. What self-directed interventions have these patients tried outside the perimeter of the formal health care system?

4. What experiences have these patients had with the formal health care system?

5. What present expectations do these patients have of the formal health care system?

Operational Definitions

Chronic Headaches

Chronic headaches are defined as recurring headaches of at least one year's duration. Underlying organic causes such as tumors, infections and structural defects had been ruled out.

Personal Beliefs

These included the conclusions drawn by the patient regarding cause and mechanism of the headaches. Also included were beginning and end point of the illness in the mind of the patient. Beliefs also included fears about the illness and major problems encountered because of the illness.

Self-Directed Interventions

Self-directed interventions are those interventions initiated by the patient through the advice of self, friends, family (or other lay persons) or by non-M.D. practitioners. These interventions were outside the formal health care system.

Formal Health Care System

This system is defined as the network of medical doctors.

Assumptions

The following assumptions were made in this project:

1. The patients are the best reservoirs of the knowledge and understanding of the illness.

2. The patient explanatory model is a true reflection of the patient's illness behaviors and beliefs.

3. A better understanding of the patient's illness behaviors and beliefs will result in better treatment and management of the chronic headache syndrome.

4. The chronic headache syndrome is a chronic illness being defined as a permanent health disorder without cure.

Limitations

The following limitations could affect the results of this investigation:

1. The patient explanatory model may not reveal all the necessary data for best management and treatment. Some of the data may indeed be superfluous.

2. The patients may not have insight into beliefs and illness and may have difficulty expressing ideas and feelings accurately.

3. Patients who consented to be interviewed may not be wholly representative of all patients with chronic headaches.

CHAPTER IV

METHODS AND RESEARCH DESIGN

Design

This was a descriptive study and the design was the first level of inquiry: factor seeking.

Setting

One-time interviews were held with private patients of a Salt Lake City neurologist. Initially, the interviews were conducted in the office setting of the neurologist. After the first 15 interviews, the remaining 28 interviews were conducted in the patients' homes. Change of setting was done because it was easier to set up appointments, and patients felt more comfortable on their own "home ground." This neurologist's practice consisted of both physician-referral and self-referral headache patients from the intermountain area of Utah, Wyoming, Idaho, and Nevada. Most patients were from the Salt Lake City area.

Population

The population was comprised of noninstitutionalized, mentally competent adults over the age of 18,

who were physician or self-referred headache patients. The patients had been medically evaluated by at least one neurologist. Underlying organic disease such as tumor, infection and structural disease had been ruled out.

Sample

Convenience sampling of this neurologist's headache patients was used. Using the neurologist's appointment book from the time period of December 1981 through February 1983, all patients were chosen with the designated chief complaint or physician referral of "headache," "migraine," "postconcussion syndrome," or "head pain." These patients were then contacted by telephone by the author. Via the phone call, the determination was made if the patient fit the described population. The author was identified as a graduate student in nursing who sought followup with these patients for a 30-minute, one-time interview. Of the first 103 patients contacted, 82 agreed to be interviewed with 44 patients finally keeping their appointments. The interviews were held in April and May of 1983. The interviews varied in length from 30 minutes to two hours with an average interview time of about one hour. One patient was interrupted midway in

the interview and referred back to a neurologist (See Chapter V).

Consent

An informed consent form was designed and each participant who consented to the interview signed the form (Appendix B). A copy of the consent was given to the participant. The consent form stated the purpose of the study, assured the patient's anonymity, and informed the patient of the right to refuse to answer any questions, to ask questions regarding the interview, and to withdraw from the study at any time without penalty or difficulties.

Instrument

The interview consisted of a questionnaire designed by the researcher combining the questions that would reflect both the medical model and the patient explanatory model to obtain an illness history (Appendix C). Open-ended questions and multiple-choice questions were included. In addition to questions asking demographic data, the interview sought answers to each of the five research questions involving: a) nature of the headache, b) personal beliefs, c) self-interventions, d) experiences with the health care system, and e) present expectations. All interviews were conducted by the

author. All answers were written down by the interviewer for later tabulation.

CHAPTER V

PRESENTATION OF DATA

The data generated from this study are presented under the following headings: a) demographic data, b) nature of description of headache, c) personal beliefs about headaches, d) self-interventions, e) experiences with the health care system and f) present expectations.

Demographic Data

The median age of the subjects was 37 years with a range of 18 to 64 years. There was a ratio of 40 females to 3 males. The years of formal education ranged from 8 years to 17 plus, with a median of 13 years. Twenty-nine subjects were married and 14 were single. Of that 14, six described themselves as divorced. The range of family incomes was from $8,000 per year to $120,000 per year with a median income of $32,000. Immediate family size ranged from 1 to 8 members with a median of 6. Number of siblings ranged from 0 to 5 with a median of 3. Median years residing in Utah was 25 years with a range from 1 to 64 years. The preponderance of subjects were originally from Utah, Idaho, and

Montana. Two were originally from California, two were from Pennsylvania. Many subjects born in Utah had moved elsewhere in their lives but had returned to Utah. Generations of family in Utah ranged from 0 to 3 with a median of 2 generations. All subjects were Caucasian. Thirty-five subjects resided in Salt Lake County with 5 residing in Davis County and 3 residing in Utah County.

Description or Nature of Headaches

As shown in Table 1, the majority of patients described the headache pain as throbbing pain (63%) or pressure sensation (59%). Other descriptions included "band-like," "dull," or "sharp." Ten subjects reported "constant pain" even though it was not listed as a multiple choice answer. There was no clear-cut categorization of answers. Some subjects used all responses as descriptions of their headache. Many described headache as having both throbbing pain and pressure sensation.

Age of initial onset of headaches was determined as being the time headaches were first seen as a "problem" by the subject. Headaches caused an interference somehow in the life of the subject. The majority of patients (58%) had developed headaches by age 18, as noted in Table 2. None of the subjects had developed headaches after the age of 44. Although data were tabulated

Table 1

Summary of Responses Describing Character of Headache Pain

(N = 43)

Description of Headache Pain	n	%
Throbbing pain	27	63
Pressure sensation	25	58
"Band-like" pain	11	26
Sharp pain	10	23
"Constant pain"	10	23
Dull pain	6	14
Type of Onset		
Slow-building onset	34	79
Sudden onset	5	12
Variable onset	4	9

Note. "Constant pain" was not one of the multiple choice answers on the questionnaire. Multiple answers to all questions were allowed.

Table 2

Summary of Data of Initial Onset of Headaches in Life of Patient

(N = 43)

Age of onset	n	%
Grade school (5-11 yrs)	13	30
Junior high school (13-14 yrs)	12	28
High school (14-18 yrs)	6	14
College age (19-24 yrs)	4	9
25-34 yrs	3	7
35-44 yrs	4	9
Greater than 44 yrs	0	0

according to chronological age, most subjects initially responded that onset pertained to a certain social period of life. For example, typical responses included: "when I was newly divorced," "out on my own," "after my fifth child," "while going to college," or "while taking care of five sons under the age of five."

In the majority of cases, no specific time of day was noted for onset of headaches as seen in Table 3. Most subjects (70%) stated that headaches could begin "anytime." The specific time of "morning" was given 19% of the time -- more than any other "specific" answer. In discussing the category, the "problem of awakening at night" held the most concern for the patients.

When describing location of headache pain, different locations of pain were noted at different times or with "different" headaches according to the subjects. The majority of headache pain in these subjects (74%) was noted to be "frontal" or "frontal-occipital" as reported in Table 4. In the six cases that noted unilateral, right-sided pain, only one location was described by the subjects. The other 37 subjects described varying combinations in their location of pain.

Three groupings of subjects were noted in defining duration of headache, as reported in Table 5. Duration ranged from a few hours to "continuous pain." Subjects,

Table 3

Summary and Data Describing Onset of Headache

As to the Time of Day

($\underline{N}$ = 43)

Time of Day	$\underline{n}$	%
"Anytime"	30	70
Morning	8	19
Evening	4	8
Awakening at night	1	2

Table 4

Summary of Perceived Locations of Headache Pain

(N = 43)

Location of Headache Pain	n	%
Frontal/frontal-occipital	32	74
Retro-orbital	10	23
Global	9	21
Bilateral	8	19
Unilateral (right side)	6	14
Ear pain	2	6

Note. Multiple answers to questions were allowed.

Table 5

Summary and Time Data Describing Duration and Occurrence of Headaches

(N = 43)

Time Interval	n	%
Duration		
few hours	16	37
6-12 hours	4	9
12-24 hours	14	33
3 days	10	23
4 days	3	7
5 days	8	19
7 days	3	7
14 days	2	5
15 days	1	2
Constant pain	10	23
Occurrence		
1-2 times/month	3	7
Once a week	4	9
2-3 times/week	9	21
4-5 times/week	13	30
Daily	12	28
Associated with period or ovulation	2	5

Note. Multiple answers to questions were allowed.

at times, described different headaches lasting different periods of time. The first grouping of subjects (79%) had headaches that lasted from a few to 24 hours. The second group of 21 subjects (49%) described duration of three to five days. Finally, 16 patients (37%) described having headaches that lasted seven days to "continuously." (Ten patients [37%] described the pain as "continuous.") Table 5 also summarized the frequency of occurrence of headaches. The largest grouping of subjects (79%) noted headaches from twice a week to daily. Further questioning revealed also that 29 (67%) patients noticed a continual "background" or "mild" headache between the "major bouts" summarized. From these subjects, comments such as "they don't go away, but I can live with some of the pain," or "my whole body aches continuously." One patient stated that "I don't notice the headache unless someone brings it up. . .like in this interview." The two patients with headaches associated with their menstrual cycles also expressed marked concern over any possibility of becoming pregnant at this point in their lives.

Factors that exacerbated headache were multiple as tabulated in Table 6. Thirty-one (72%) subjects identified exercise or movement as making headaches worse. The next largest grouping identified alcohol,

Table 6

Factors Identified as Exacerbating Headache Pain

(N = 43)

Factors	n	%
Exercise or movement	31	72
Alcohol	12	28
Stress	12	28
Chocolate or sugar	11	26
Fluorescent lights	10	23
Smoking or presence of smoke	10	23
Other strong smells	7	16
Being over-tired	7	16
Presence of other people	6	14
Sounds of any kind	6	14
Shouting or yelling	4	9
Caffeine	2	5
Chewing food	2	5

Note. Multiple answers to questions were allowed.

chocolate, sugar, fluorescent lights, cigarette smoking, and stress as exacerbating factors. Even cheering and shouting at basketball games was a major exacerbating factor for four of the subjects. Thirty-four (79%) stated that the headaches usually got worse as the day progressed. Nine stated that the headache remained the same or worsened. No one stated that the headaches lessened throughout the day.

The associated symptom of nausea was reported in 39 (91%) of the respondents, as noted in Table 7. Blurred vision and irritability were noted by almost half of the subjects. Vomiting and dizziness were reported by one-fourth of the subjects. Table 8 summarized the specific symptoms associated with the aura preceding headache pain. Twelve patients (28%) reported an aura with nasal congestion, visual disturbances and/or facial and limb paresthesias as the noted symptoms. (One patient described recent onset of a "scorched taste and smell sensation" before her headaches. Since this "sensation" may herald a temporal lobe dysfunction the patient was dropped from the sample and was referred immediately back to her neurologist.) No "prodromes" were reported despite specific questions.

In summarizing measures of relief (Table 9), 36 subjects (84%) found that sleeping or lying down was the

Table 7

Associated Symptoms Reported with Headache

(N = 43)

Symptom	n	%
Nausea	39	91
Blurred vision	21	49
Irritability	17	40
Vomiting	10	23
Dizziness	10	23
Chills	3	7
Abdominal pain	2	5
Flushed feeling	2	5

Note. Multiple responses to questions were allowed.

Table 8

Symptoms Experienced with Aura Before Onset of Headache Pain

(N = 43)

Symptoms	n	%
Nasal congestion	9	21
Visual disturbance (scotomata or other)	8	19
Numbness and tingling of face or limbs	7	16

Note. Multiple responses to questions were allowed. Twelve patients (28% experienced an aura with headache.

Table 9

Summary of Measures that have Brought Relief for Episodes of Headache

(N = 43)

Self-intervention or behavior	n	%
Relaxing, lying down or sleeping	36	84
Analgesic drugs	14	33
Eating	9	21
Coffee, caffeine	9	21
Muscle relaxant drugs	6	14
Heat	6	14
Ice	5	12
Diuretics	3	7
Nothing	3	7
Increased salt intake	1	2

Note. Multiple responses to questions were allowed.

most effective means of coping with a headache. Only 14 patients (33%) allowed that analgesic drugs lessened headaches. Other methods such as ice, heat, eating, or intake of caffeine lessened pain in 20% or fewer of the patients. Three reported that nothing tried had alleviated headache pain.

When asked about a familial history of headaches, 34 (79%) reported a positive history. Seventeen (40%) also reported their spouses as having headaches. Eight (19%) responded that there was also a family history of colitis (this response was spontaneous, as the subjects were not questioned regarding colitis or other "possible psychosomatic chronic illnesses").

Personal Beliefs About Headaches

Most responses to the question, "What causes your headache? -- Explain the mechanism" were restatements of trigger factors as listed in Table 10. Main causes identified were tension or stress. Only a few patients had any thoughts or insight regarding the mechanism of headaches. Nineteen stated that they had "absolutely no idea what caused the headaches." When pressed for a mechanism some responses were: "My body reacts crazy to stress," "I have a physical stress on my neck muscles," "tension causes muscle contraction which causes pain," or "something is structurally wrong with my head --

Table 10

Summary of Responses to Beliefs About Causes/Mechanism of Headache

(N = 43)

Causes/Mechanism	n	%
Tension or stress	24	56
"No idea"	19	44
Depression	3	7
Pinched nerves	3	7
Lack of emotional support	2	5
Reducing diet	2	5
Fatigue	1	3
Hormonal changes	1	3
Menopause	1	3

Note. Multiple responses to questions were allowed.

'they' just can't find it yet." One person responded that "tension sets off a pain syndrome in my brain and neck." Other comments included "it's just part of my life," "it's just the way I'm made," or "some people have ulcers, I have headaches."

Most subjects seemed surprised or confused by the mechanism questions. Most had difficulty coming up with answers. While 24 subjects identified stress as a trigger factor, it was uncertain or unknown to them why stress would result in a headache. When asked, "Why do other people have stress and not have headaches," the subjects were unable to give a definite reply. A few subjects did state that nonheadache sufferers "did not have stress as headache patients did."

Table 11 summarizes the responses to the question, "Why did your headaches start when they did?" Most subjects stated that a specific life stressor was responsible for the onset of headaches. However, the subjects gave no explanation why the headaches then continued and became chronic (further explanation was not requested during the interview). Life stressors such as "getting married," or "getting divorced" were stated. The most interesting "cause and effect" phenomenon was related by a 36-year old woman who stated that she ate hot dogs when she was 11 years old,

Table 11

Summary of Responses to Why Headaches Had Their Onset

(N = 43)

Responses	n	%
Not coping with stress at that time	15	35
"No idea"	15	35
Many problems	7	16
Auto accident	7	16
Body changed	7	16
Getting married	4	9
Getting divorced	3	7
Overachiever	1	2
"Ate hot dogs once at age 11"	1	2

Note. Multiple responses to questions were allowed.

developed severe headaches and "has had headaches ever since." Her headaches persisted despite the fact that she had eliminated hot dogs from her diet 25 years earlier. Fifteen subjects (36%) were unable to to give any reason for the timing of the onset of headaches. Those who responded that an auto accident caused the onset of headaches stated that the accident "damaged nerves or muscles." (Nerve conduction studies and electromyelograms in these patients' charts did not show degeneration or damage).

When asked to rate the pain of their headaches on a scale of 1 to 100, with the latter being the most severe pain imagined or felt, 40 (93%) of the patients ascribed "one hundred" as the rating for headaches experienced. Two reported worse pain with renal colic (kidney stones) and one subject was equivocal stating that the pain with headaches was "about the same as pain from a broken back in a car-pedestrian accident."

"Will these headaches be something that will always be with you, or will they stop someday?" was the next question. Thirty-eight subjects (88%) responded that they will always have headaches. These subjects qualified this response with statements such as "I've been to many specialists -- none could help," "I hope something comes along," "I pray they stop" or "I was told by my

doctor that I'll always have them." Only one response showed a locus of control within the patient with the statement, "I may get fewer headaches as I get control of my life." While three subjects (7%) had no idea at all if headaches would stop, two (5%) did answer that the headaches would stop someday. These latter two subjects stated that they were guaranteed by their physicians that the "headaches would be cured."

The respondents perceived both temporary and permanent harm from headaches. Temporary harm revolved around social behaviors. Perceptions of temporary harm included such statements as "unable to be active in church," "I don't accomplish much anymore," "can't concentrate," "can't study," "I treat people differently. . .will that have long-term effects?" So, in addition to daily physiological pain, these patients also experience a painful decrease in cognitive and social functioning.

Permanent harm was deemed physical harm. Permanent damage is seen as resulting from the pain itself or from possible long-term effects of the medications. Qualifying statements included: "I'm going downhill each day," "severe pain is changing me," "the pain makes me old looking," to "the medications are changing me. I'll never be the same."

All patients expressed fears. It was expected that many would be afraid of tumors or cancers, but other fears were also brought out. Fears included: "the headaches will kill me," "that my arteries will burst," "I'll vomit and aspirate." But much of the fear was aimed at the pain experience itself. These fears were relayed in comments such as "afraid I'll never be free of pain," "that the pain will never go away," "afraid that the pain will just get worse and build to the point that it will never go away." These latter statements were a common theme in the interviews. These subjects were very worried that pain would take total control of their lives.

Table 12 summarizes the chief problems encountered because of chronic headaches. All 43 subjects had experienced major upsets in activities and relationships. Interestingly, only 12 (28%) stated having problems with self-concept or self-esteem. Comments given indicated that many subjects had rearranged lives to compensate for existing or possibly impending headaches. Included comments were: "I can't schedule anything -- what if I get a headache?" "just can't go back to work," "can't read or think," "my kids have become the adults in the family," and "I've given up fun times and recreation." These fairly discouraging statements were

Table 12

Summary of Major Problems Encountered with Chronic Headaches

(N = 43)

Problems	n	%
Interference in activities of daily living	35	81
Interference with social interactions	35	81
Stress on work role and working relationship	35	81
Stress on family relationship	34	79
Interference with recreational activities	25	58
Problem with self-esteem or self-concept	12	28

Note. Multiple responses to questions were allowed.

representative of many more. Two statements that summed up the main ideas were: "I've given up even trying to do anything else in my life other than care for my headaches" and "headaches definitely keep you from having a good time." If the description of health is "to live, work, and love well," then these people are far from healthy.

Experiences of Self-Directed Intervention

Outside the scope of the formal health care system, subjects were asked what self-directed interventions had been tried for relief of headaches (Table 13). Responses varied from six subjects (14%) who had never tried any self-directed interventions to one patient whose wife had even learned chiropractic procedures and had built a special massage table. Most had tried over-the-counter analgesics, while about half had tried heat or cold for relief. One of the four subjects who had tried exercise, had read that "jogging increased cerebral blood flow which decreased headaches," but said jogging exacerbated her head pain. In retrospect, some patients noted that when actively engaged in routine exercise, gymnastics or aerobics, headaches were decreased, but recent attempts at exercise resulted in headaches.

Overall, there were few imaginative interventions on the part of the subjects. Most subjects could

Table 13

Summary of Self-Directed Interventions

(Outside Formal Health Care System)

Tried for Relief of Headaches

(N = 43)

Self-intervention	n	%
Taking aspirin (or aspirin containing compounds)	26	60
Heat	20	47
Cold	19	44
Taking acetaminophen (or acetaminophen containing compounds)	17	40
Herbs	14	33
Taking antihistamines	8	19
Miscellaneous[a]	6	14
Physical therapy	5	12
Exercise	4	9
Quit smoking	3	7
Quit caffeine	3	7
Tried nothing on own	6	14

[a]

Note. Other interventions including stopping sugar or chocolate, using oxygen, changing lifestyle, self-taught acupressure. Multiple responses to questions were allowed.

not remember origin of ideas of self-intervention, but listed "family," "friends," "magazines," and "television" equally. Only four subjects had bought books or magazines expressly for the purpose of finding out about headaches.

As reported in Table 14, most subjects (70%) began treatment of headache pain only with increased pain or when activities were interrupted. The latter phase was not one of the multiple choice answers. Some of the qualifying statements included: "I start treating my headaches at the first warning sign, but I know I'll end up in an emergency room no matter what I do," "When I start getting increased pain, I stop everything," and "I spend most of life looking for warnings trying to treat the headache, or enduring the headache -- it's taken the place of my family and all my old activities." Four of the subjects never tried any treatments because "nothing worked anyway." A disturbing theme also found in this category was the majority of respondents who would take narcotic pain medication for prevention of any onset of headaches. Even if the headaches occurred, the analgesics "at least made me feel good." Eighty-five percent of the subjects only reported mild or no relief with self-directed treatments. Responses also stated were: "If I don't get rid of this headache, at

Table 14

Summary of Responses to Question "When Do You First Start Treatment for your Headaches?"

Response	n	%
First warning	6	14
First pain or discomfort	3	7
With increased pain	20	47
With associated symptoms	0	0
Only when it affects activities	10	23
No treatment	4	9
"What relief do you get with these treatments?" (self-intervention) (of 39 who tried treatments)		
No relief	10	26
Mild relief	23	59
Good relief	4	10
Varies	2	5
"What relief do you get with treatments recommended by professionals?"		
No relief	11	25
Mild relief	32	75
Good relief	0	0

least I feel pretty good about myself for trying," and "no matter what I try, it will be of no effect, the headache has to run its course." One especially halting statement was "I can cope; if I'm vigorous enough with treatment, sometimes the headache won't return for a day or two."

As seen in Table 15, a surprising number (37 subjects, 86%) of patients had seen chiropracters. The comments regarding all these practitioners were mild and fairly nonjudgmental. Typical comments included: "I have seen the chiropracter three times a week for the past year -- he seems to be helping -- I guess." "I go to the chiropracter twice a week -- occasionally he helps the pain," "I get so desperate that I'll try anything... I've even been to a blind osteopath." "Herbs change your body chemistry so that you won't have headaches anymore." One interesting statement was "I tried a herbal life diet plan that replaced two-thirds of my meals -- I tried it for a month, but it didn't seem to help" -- that is real compliance and will power. Other comments about the folk practitioners were "they lessened the tension," "they're easy to get into," "they're not very expensive" and "they don't help a lot, but at least it's something." Most patients had not told their neurologist about these non-M.D. folk practitioners.

Table 15

Total Number of non-M.D. Practitioners Consulted by Respondents

(N = 43)

Non-M.D. Practitioner	n	%
Chiropracter	37	86
Herbalist	12	28
Naturopath	6	14
Others[a]	6	14
Osteopath	3	7

[a] Other practitioners who used iridology (study of the iris of the eye in relation to systemic disease), acupressure, acupuncture, and massage.

Note. Multiple responses to questions were allowed.

As seen in Figure 2, satisfaction with these practitioners was split. Only nine subjects stated that they would not return, while 28 stated that they might or would return! To this answer a common comment made was, "If the medical treatment doesn't work, I still have the chiropracter."

Experience with the Formal Health Care System

The health care practitioners seen by these 43 subjects are summarized in Table 16. A total of 207 professionals were seen, resulting in an average of 4.8 practitioners/patient. These subjects were both self- and physician referred. Comments showed that the subjects were unclear about the different specialties of physicians seen, or the reasons for referral. Typical comments were "I was sent to a neurologist for an EMG, but he didn't treat me. . .he just did a test" or "I went for a CT scan of my brain, and the neurologist explained the results, but didn't examine or treat me." In neurological practice, both test referrals are common, but this was not clear to patients. One woman commented that after her gynecologist did a routine pelvic and breast exam, "he gave me a hormone shot to clear up the headaches I had mentioned during the history."

Although the questionnaire did not ask for

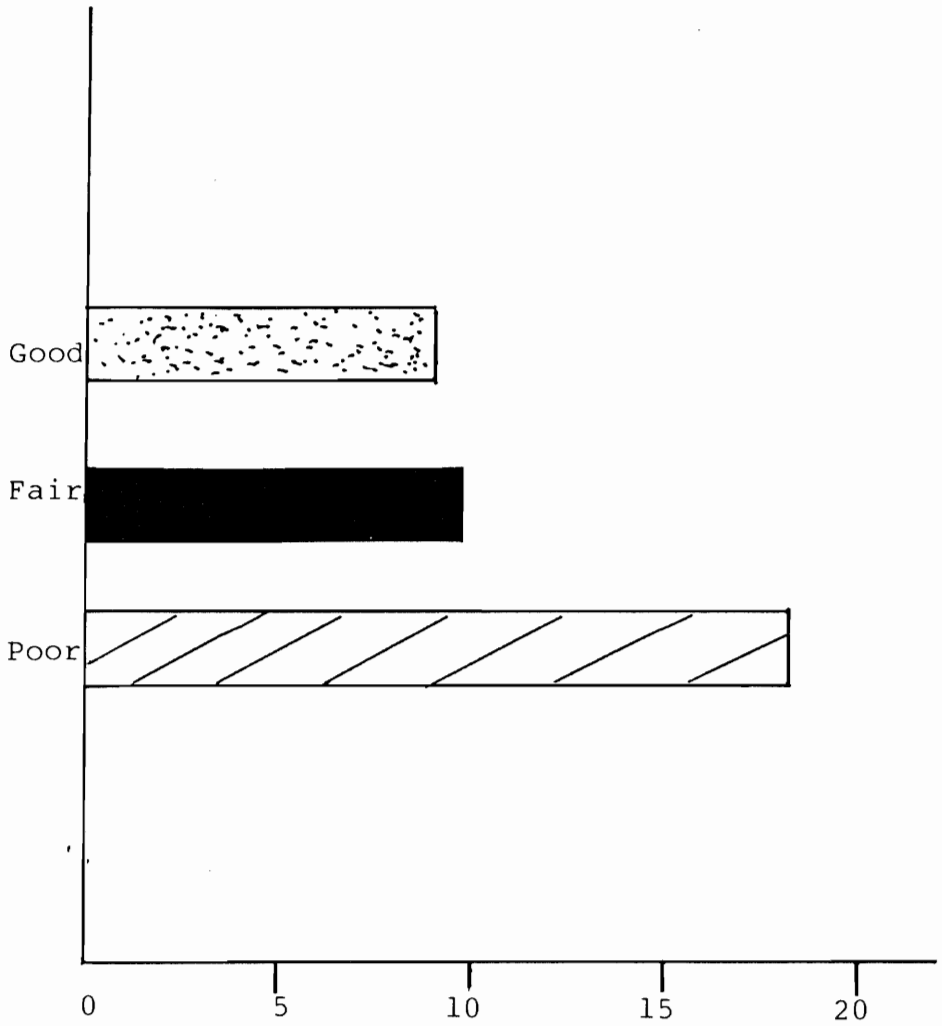

Figure 2. Satisfaction with non-M.D. practitioners (n = 37)

Table 16

Total Number of Individual Health Care Professionals Consulted by Respondents

(N = 43)

Health Care Practitioners	N
Neurologists	71
Internal Medicine	34
Family Practice	30
Psychologist/Psychologist	16
Ear, Nose and Throat Specialist	11
Orthopedist	9
Physical Therapist	9
Opthamologist	8
Obstetrician	8
Pain Clinic	6
Orthodontist or Dentist	3

Note. Multiple responses to questions were allowed.

definition of the neurologist's specialty, there was much confusion surrounding his role. Most patients did not view the neurologist as a primary care provider. The neurologist was not seen as a person for follow-up or advice. Most viewed the neurologist as a one-time consultant "who could figure out exactly what was wrong and then cure the headache." The majority of subjects thought it incomprehensible to call the neurologist for problems or make follow-up visits.

Table 17 summarizes the types of treatment and referral, and intervention suggested by the medical practitioners. As noted, many patients did not comply or follow-up with treatment. Sixty-five percent of those referred for counseling did not go -- "He (the doctor) told me it was all in my head -- I already knew that -- that is why I went to the doctor." One hundred percent received drug prescriptions but as 37% felt, "why get the prescription filled -- I already knew that drugs didn't work," or "I never get my 'scripts' filled, and I never went back either, I couldn't afford to hear the same advice over again."

Physical therapy, biofeedback, lab tests, EMGs, surgery, x-rays and changes in diet and lifestyle were suggested. Three were even referred back to previous chiropracters -- but the common comment made was

Table 17

Summary of Advice, Treatment, or Referral from Health Care Professionals

(N = 43)

Advice, Treatment or Referral	N	%
Drug prescriptions or samples	43[a]	100
Psychotherapy, counseling referral	23[b]	53
Physical therapy	19[c]	44
Biofeedback	15[d]	35
Lab tests, electromyelograms	13	30
Change in diet	8	19
Surgery	8[e]	19
X-rays, CT scans	6	14
Change in lifestyle	3	7
Return to own chiropracter	3	7

Note. Multiple responses to questions were allowed.

[a] 16 respondents did not have prescriptions filled/or stopped samples after a few doses.

[b] 15 respondents referred did not follow-up on referral.

[c] 2 respondents did not follow-up.

[d] 4 respondents did not follow-up.

[e] 3 respondents declined surgery.

"anything new seemed to work for a short time. . .then it stopped working again." When questioned, subjects had shrugged off intervention of counseling as superfluous, not having serious intent. Table 14 summarizes the relief brought by medical intervention. More patients stated that they received more relief from self-directed interventions than from medical intervention. However, those who did want narcotic analgesics were happy with that part of the medical treatment -- "at least he still gives me Fiorinal."

Twenty-one patients reported being diagnosed with both "migraine" and "tension" headaches. Ten patients stated that no specific diagnosis had been made. One patient stated the headaches were due to "biochemical imbalances" even though "no lab tests were done." She was quite indignant and upset -- "How could he diagnose that without a sample of my blood?"

An hypothesis of biochemical imbalance is given as a cause for headaches among current headache diagnosticians. If this hypothesis were referred to, in the course of consultation, the patient could become confused by its meaning, as the patient did. One subject was upset when given the diagnosis of "tension headache." She had misinterpreted psychic tension for muscular tension.

The largest number of comments in the entire interview was generated about satisfaction with the medical system. As noted in Figure 3, 33 patients (77%) described their satisfaction as poor while ten (23%) described it as only fair. No one described satisfaction as good. Representative comments are as follows: "I wanted insight into my illness, not another prescription," or "it seems like all they ever tell is that I have a headache. . .I already knew that." One-word comments such as "disgusting," "yuk," "worthless" were made. Some evaluations were basically close to the truth -- "it all seemed like a guessing game," "trial and error," or "ambiguous with no set direction or goal." Communication was a problem. "I wanted to tell him that I was dissatisfied with his advice, but I was afraid that he would think that I was crazy or uncooperative." "I wasn't given enough information." Confusion was again expressed: "Each doctor I've gone to has given me a different diagnosis." Many could not remember having a neurological physical examination performed. If they did remember an exam, they didn't understand how the exam fit in with diagnosing headaches.

One summary statement that fit many feelings was: "I had increasing headaches for years, and so "they" [his

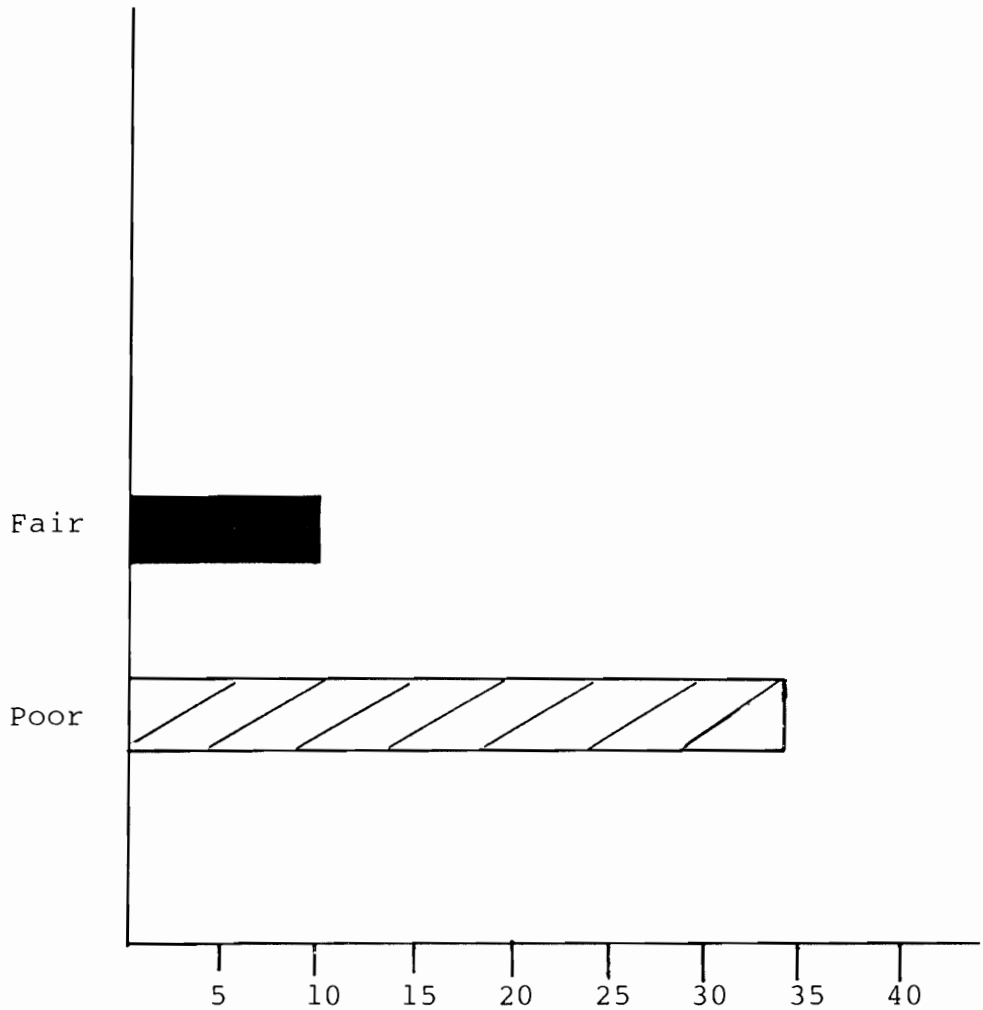

Figure 3. Satisfaction with former (medical) health care practitioners (n = 43). No one responded that satisfaction was good.

doctors] made the big decision for me to have an EEG, CT brain scan and other lab tests and x-rays. They were all normal. But it didn't change the fact that I still had constant headaches. . .I just seemed to be brushed off by the doctors after that . . .as. . .well, they had done their job!"

Some tried to "let their doctors off the hook" with statements such as: "I think he did as much as he could," "it's probably my fault anyway" or "headaches can't be cured anyway."

But as one woman patient put it so well, "I just expected more somehow. . .couldn't I just learn to handle my headaches?" When these patients were questioned as to whether fears had been resolved through medical consultation, only four (9%) replied "Yes." Sixteen subjects (37%) had partial resolution of fears, while 23 (53%) stated that their fears had not been resolved.

Present Expectations

Twenty-eight of the patients were referred by physicians. Three patients were self-referred and 12 were referred by the spouse. Of the 28 physician referrals, six were at the continued urging by the patient for referral.

As seen in Table 18, results expected by the

Table 18

Summary of Expected Advice, Treatments, or Referral by Present Neurologist

(N = 43)

Advice, Treatments, Referral	n	%
Cure for headache	40	93
Insight into illness	40	93
Just someone who will listen	32	74
Advice for dealing with pain	27	63
Lab tests, electromyelograms	27	63
X-rays, CT scans	26	60
Drug prescriptions	19	44

Note. Multiple responses to questions were allowed.

patient was straightforward. A "cure" was wanted. Advice, insight, and someone who would listen were also sought. Twenty-six of the subjects (60%) expected CT scans, x-rays and lab tests as this was seen as a straight path to diagnosis. Some representative comments included "wanted different alternative from drugs," "surprised not to get x-rays -- how could they tell what was wrong with me otherwise?" and "I thought he would look more extensively at what was wrong with me." Some patients went in expecting an impossible situation, "I wanted something in one session that would cure my headaches," or "Gee, all I wanted was more Fiorinal." However, only 19 (44%) expected drug prescriptions.

In keeping with the running theme of the interviews, all 43 patients wanted "a cure," as noted in Table 19. However, another common response was "assurance that the headaches won't kill me" The patients also wanted to understand the cause, and wanted lessening of the pain and stress associated with the headaches.

These patients stated a willingness to expend time and energy toward alleviating the headaches. Thirty-seven answered "alot of time" or "as much as it takes." Six stated a willingness to expend "some time and energy."

Table 19

Overall Results Expected from Consultation with Present Neurologist

(N = 43)

Overall Results	N	%
Cure for headache	43	100
Assurance headaches will not be fatal	37	86
Knowledge of cause of headache	32	74
Decreased pain (if cure not possible)	23	53
Decreased stress	7	16

Twenty-two of the subjects (51%) felt that the practitioner and the patient should share equal responsibility for effecting control of the headaches. Thirteen patients (30%) gave all the responsibility to the practitioner. Four subjects shouldered all the responsibility, while four subjects were not sure who should have the responsibility. Representative comments included: "we [the practitioner and the patient] start out as equal partners, but then I take on more responsibility," or "I didn't realize that I would have to do any work to get rid of the headache" to "I might help out if I'm convinced that there is a permanent cure." Two comments worth ending this section on expectations are: "Should I take on some of the responsibility? -- I've spend $12,000 over the past four years for medical care and tests -- does that give you a hint?" and "Medicine doesn't have the answer, but then I don't know who does."

CHAPTER VI

DISCUSSION OF FINDINGS

General Findings

When headaches are approached as a "disease" by the health care system, using the medical model, the patient's needs and expectations are not met. Chronic headache patients in this study perceived headaches as a chronic entity of pain that is out of the patient's locus of control. No clear categorization of headaches was noted in the majority of patients. When the patient explanatory model is used, personal beliefs, previous experiences and interventions, and present expectations are brought out in the history. The patient, along with the illness of chronic headaches, can then be managed more realistically.

The chronic headache patients are in real distress with this illness. Life patterns have been rearranged, recreation has been stopped, relationships have been altered in adaptation to this illness. These patients are very fearful of the sometime daily, almost constant pain. These patients should not be viewed as lazy, noncompliant, or manipulative, but rather as misdirected,

naive and irresponsible. Irresponsible in that the locus of control of responsibility for the chronic headaches has been placed in the hands of the practitioner rather than on themselves. Another consideration is that this loss of control may not be indicative of chronic headache patients, in general, but may be characteristic of this homogeneous demographic group.

Confusion and lack of communication have been the major components of the practitioner-patient relationship. The practitioner and patient have widely divergent expectations with respect to diagnosis, follow-up and treatment. The practitioner, using the medical model, rules out structural, organic disease, labels the "disease," then relies on stock methods of drug treatment and further referral. The patient desires a "cure," insight, advice and methods to control the pain experience. The patient wanted resolution of the fears accompanying this illness. The patient needs to see the practitioner as available, open and caring.

Demographic Findings

The sample studied was comprised mostly of middle-to-upper income Utah middle aged women. Most were married or had been married. Are chronic headaches an illness of this population? Or is it just

that this group presents to a neurologist's office more often than the rest of the population? Perhaps because of their income and education levels, solutions and interventions had always been bought before with money. The solution to all problems is money, specialists, and technology. There was no need to learn or try self-directed interventions if someone else could be paid for the solutions.

Why did the participants respond to the interview as opposed to the 59 who refused outright or failed to show as planned? Perhaps these individuals were still looking for that expert opinion, that person who would give them the final insight -- the magical cure. Perhaps the other 59 felt that enough was enough; nothing had worked before and this graduate student was not going to make any difference either. Why go through the whole "story" again and still end with no results?

Description of the Headaches

Despite the fact that many of the participant's were categorized as "tension" headaches, most patients seemed to have a major vascular component of the headache. This can be inferred from the significant numbers who had nausea, "throbbing" pain, dizziness and auras.

Ninety-one percent of the subjects reported nausea

with the headaches. This overwhelming percentage is not supported in textbooks (Dalessio, 1980; Diamond, 1981), but represents an associated illness. Blurred vision was noted by 49% -- another symtpom that may well be vascular in origin. Associated symptoms classified in textbooks (Dalessio, 1980; Diamond, 1981) such as polyuria, tremor, vertigo, swelling, diarrhea and weakness were categorically denied. Perhaps a larger sampling was needed to find the symptoms.

Nasal congestion was described by 21% of the subjects as an aura or warning of the impending headaches. Congestion was the most predominant aura noted by the subjects, yet it usually is not mentioned in texts. Since, as mentioned before, so many patients do describe "vascular" phenomena, nasal congestion (indicating vasodilation of the nasal vessels) may portend or symbolize the overall change in cerebral vascular instability. "Symptomatic" relief with decongestants may well abort the headache. This symptom of nasal congestion may be showing an allergic reaction to an environmental allergen. It would seem worthwhile to further investigate any allergic history and refer for allergan testing.

Migraine prodromes were not reported by any of the subjects. Since the prodrome events may occur up to 24 hours before the headache, precise journals, marked

insight, or remarkable memory for reverse logic would be necessary to elicit the prodromes if they do exist. Prodrome events are often mentioned by headache text authors who suffer headaches themselves. Their self-diagnosis and symptom evaluation are, needless to say, in prominent detail and probably result from painstaking diaries. This is in sharp contrast to the typical chronic headache patient in this sample. A migraine prodrome may simply be a culmination of all the different stresses (negative as well as positive) occurring in the participant's lfie. Because of these stresses, a threshold is reached, then bypassed, and the headache begins.

Personal Beliefs

The cause and effect of headaches seemed to be ignored by this sample. For example, one woman stated that fluorescent lights always worsened the headaches, yet in recent remodeling of her kitchen, installation of new fluorescent lamps was allowed. Another subject identified caffeine as an exacerbating factor, yet conceded that she drank "seven to eight cola drinks a day." Perhaps this was the first time insight was ever used in trying to identify any exacerbating factors.

Seventy-two percent of the subjects noted that

headaches were exacerbated by exercise. Aerobic exercise does certainly increase intracranial pressure, cause vasodilation of cerebral vessels, and raise blood pressure which all put pressure and extra stress on already painful cerebral structures.

Also of interest is how the subject's lives have been totally rearranged; and carefully patterned to "allow" for constant and unpredictable interferences by headaches. Favorite pastimes or recreation have been discarded to be "on guard" for headaches. Or has headache behavior allowed the subject to stop activities or avoid situations secretly felt to be unwanted? Now, without too much fear of reprisal, the subject can finally say "no" to events and people. The mother who states that her "children are the adults now and take care of" her may be fulfilling a latent wish to be dependent and cared-for again. The latter feelings are probably in the minority, but attention must be given to searching out these feelings. Another form of support must be taken into account by the practitioner before taking away the patient's "coping mechanism."

Experience with Formal Health Care System

The patient was frustrated with the health care system's inability to specifically diagnose and then

treat (cure) headaches. Frustration leads to noncompliance with any follow-up, medications or further treatment and referral. Patients knew that medications did not work before, so why should drugs work now? Another referral meant one more health care professional who could not again cure the chronic headaches.

Behavior is not changed; new ways of coping are not discovered. The chronic headache cycle goes on. There also does not seem to be communication on the part of the practitioner to maintain the position that "I have the answer. . .I know what is best for the patient," when the patient gets no relief from pain from that type of thinking. Rather, the practitioner needs to be flexible to mold a therapeutic program for the individual rather than force the patient into a stereotyped role.

Perhaps non-M.D. practitioners were more "approachable" to the sample, and so areas of concern and problems were more easily broached than with the formal health care practitioners. The subjects felt that these non-M.D. practitioners really listened. The non-M.D. practitioners seemed to always be available for appointments without much waiting. Appointments sometimes up to three times per week were used. The subjects always felt welcome and questions were always answered.

The subjects felt free to ask questions. These non-M.D. practitioners had charts and diagrams and could "point out exactly where the problem was."

Another aspect of health care seen as negative to the subjects was a referral to the emergency room for medical intervention for the severe headache. This is a real war zone. The patient only wants pain relief for the severe, incapacitating pain. If the private medical practitioner "called in" an intramuscular injection, the subjects reported being made to feel like a drug abuser. Charts are pulled to see when the last injection was, and "drug abuser" lists were consulted or "updated." If the patient was referred without a drug injection order, then a medical/ethical problem exists for the emergency room staff. The medical obligation is to rule out underlying structural disease and/or not be "conned" by "another drug abuser" looking for a narcotic injection. This presents a real dilemma for the staff and headache patients may never be given anything for pain relief or reluctantly a small dosage of non-narcotic analgesic. The patient with chronic headaches becomes a victim again.

Resolution of fears by health care practitioners was not accomplished according to the subjects. In a study by Fitzpatrick (1981), most neurological outpa-

tients were not reassured of not having serious organic disease. If not reassured, most were dissatisfied with care. Fitzpatrick felt that this directly correlated with noncompliance in follow-up and treatment.

> In 40% of the cases, neurologists had not even recognized the presence of worries about serious illness and so were not in a position to provide more appropriate explanations (Fitzpatrick, 1981, p. 330).

As described previously, the dominant fear of pain is probably never even identified or pursued by either patient or practitioner. All fears may never be totally resolved, but better attempts can be made at identification and resolution.

Present Expectations

It was of interest to note that in present neurologist referral, of the 15 nonphysician-referred patients, 12 were referred by the spouses not by the patients themselves.

> Patients who come to a physician involuntarily at the insistence of relatives, friends, or other physicians are often less cooperative and thereby indicate an inability to accept responsibility for their recovery or for maintenance of good health. Be alert for signs of patients' sense of personal responsibility (Polley & Hunder, 1978, p. 80).

The subjects expected advice, insight, and counseling, in addition to a "cure" for the headaches. These are straightforward expectations, but for the most part are impossible. Patients expected that the neuro-

logist would know exactly the cause of the headache and thus exact a cure -- a germ theory for headaches. Health care has not found that "magic bullet" for headaches; health care is barely alleviating the symptoms now. The patients expected insight and advice, yet when referred for counseling did not go, or stopped after only a few sessions with the psychotherapist. Perhaps, again, the subjects had difficulty with a cause and effect relationship here. "How could psychotherapy take my head pain away?" Psychotherapy also means not being "mentally stable," "abnormal" to some patients. No, the subjects were hoping for immediate instillation of insight by the neurologist at that first appointment. Having the pain of the headache is enough, the patients do not want the responsibility too.

CHAPTER VII

SUMMARY AND IMPLICATIONS

Demographic Data

The population surveyed were predominantly middle-to-upper income, Caucasian, married females ages 35 to 40. The average education was high school plus at least one year of college or vocational training. There was a strong representation of long-term Utah residents along with former Idaho and Montana residents. All together, the surveyed group was a very homogeneous population. This sample group seemed representative of the entire population of headache patients at this neurologist's office.

Description of Headaches

Overlapping descriptions of headaches prevailed in the interviews. Head pain was both "throbbing" and "dull" at the same time. Pressure sensation was described along with sharp pains. Description was very individualistic as opposed to fitting into neat categories as described by Dalessio (1980) or Diamond (1981). Time of day of onset was also so variable that descriptions

did not fit into any time-honored molds. Awakening at night with headaches brought many distressed comments as if this were the final, rudest invasion of privacy. Seventy-two percent of the subjects were having chronic headaches by high school age. The illness was established early in adolescence. The duration and occurrence of the episodes of the headaches are remarkable. It becomes more of an adventure to establish "headache-free" periods of time. For ten of the patients, headaches were constant; there was no headache-free period.

Identified exacerbating factors were usually present in the immediate environment of the subjects, or were usual behaviors of the subjects. However, no or little effort was aimed at eliminating the factors.

A strong familial history of headaches was present. The subjects also reported a high percentage of spouses with headaches. Patterns of living seemed to be as important in perpetuating and maintaining the illness as heredity. Twenty percent also reported a familial tendency toward colitis. This latter information was voluntarily given. The subjects were well aware of the psychosomatic illnesses.

Personal Beliefs

Subjects had relatively little insight into trig-

gering factors and mechanisms of headaches. Coexistence with headaches seemed to have become a fact of life without cure or answer. The headaches existed -- what else was there to know? Once headaches began in adolescence (or younger), headaches became a permanent unwelcome guest. Thought was not really given to how the guest came to be there. Blame for the headaches was mainly put on outside sources: auto accidents, marriage, divorce, college, high school, life stresses, and body changes. Headaches were never seen as a learned behavior for dealing with the world's reality. Development of this inefficient (or efficient) coping mechanism (Cockerham, 1978) was not seen by the subjects. One subject did state that she had learned to see the headaches as an "escape valve." Development of headaches meant time to slow down and retrace steps for her. For the most part, chronic headaches had prevented most of these patients from living wanted, active, and useful lives.

The subjects had given up the locus of control for controlling or ameliorating the headache pain to the formal health care team and non-M.D. practitioners. "They" (the medical profession) should cure the headaches. While 100% "hope" for a cure, 88% despondently state headaches will be a permanent part of life.

A surprising concept found was that the predominant fear expressed was the pain experience itself. Medical knowledge has been aimed at ruling out underlying organic diseases such as tumor or arterial-venous malformations as a basis for headaches to "put the patient at ease." But the number one fear of severe pain is really not fully addressed in current health care.

Experiences of Self-Directed Intervention

As mentioned previously, the idea of using self-directed interventions was not commonly thought of or used in this sample.

However, one recurring theme noted when these self-directed interventions were used was the willingness and compliance of these subjects. Trying whole-scale herbal diets for a month or seeing chiropracters and osteopaths. for years on a thrice-weekly basis required much energy and time. The interview did not delve deeply into the reasons that the subjects used non-M.D. practitioners so commonly. Overall, the practitioners were seen as "nonprofessionals" who were "at least trying to help" and "who would listen." A cure was not really expected.

Experience with Formal Health Care System

Many neurologists and other medical doctors were consulted by the subjects. Here was the reservoir of knowledge that should have contained "the answer" and "the cure" for the chronic headaches. Instead, communication was minimal and confusion was abundant. Private medical doctors referred these patients to neurologists, orthopedic surgeons, ear, nose and throat specialists and pain clinics. No one seemed to assume final responsibility for the patient and the chronic headaches. On the other hand, the patient expected a cure on the first referral and when none was offered became "angry and wouldn't return!" The patient was frustrated with the health care system's inability to specifically diagnose and then treat (cure) headaches.

Any referral for couseling was shrugged off as superfluous or not seen to have serious intent by most patients. The connection between actual head pain and psychological/behavioral problems was not perceived. Since structural disease was seen by the patients as the basis for headaches -- that is why the subjects went to neurologists, orthopedic surgeons and internists in the first place -- for them, it did not make sense to be referred to a psychologist now.

Overall relief with medical intervention was

minimal or none, but when such high noncompliance was noted as the rule rather than the exception, evaluation of amelioration of head pain was impractical. When headaches were categorized, and patients were given a specific headache diagnosis, the patients had some emotional dilemmas. Patients were "relieved" to have vascular or migraine headaches; these patients then assumed no personal responsibility for the headache's existence. Migraine patients, however, tended to work harder for treatment and a "cure." Patients who were told that they had tension headaches felt "belittled" or "betrayed," as if tension headaches were a common, vulgar illness of no real significance. Having tension headaches meant a "weakness" in personality. These subjects diagnosed with tension headaches felt no control in treating or "curing" the headaches.

Overall satisfaction with the health care system was dismal as described above. Satisfaction was higher with non-M.D. practitioners, but the subject expected much more from the health care professionals and were, therefore, more upset when a cure was not available.

The one area of satisfaction noted with health care practitioners was the availability of narcotic analgesics. This was a disturbing, recurring theme in the interview. The intention of the prescriptions for narco-

tics was for interruption of acute pain episodes with chronic headache patients. These drugs were perceived by many patients to be absolutely necessary to "ward off pain," on a daily basis if necessary. Pain was such a feared entity that a ready supply of narcotics was always required. However, narcotics were also used prophylactically to prevent headaches from even occurring. If the headache did occur, doses much higher than prescribed were used to keep the pain from worsening. Prescriptions for 36 Percodan or Demerol would be used in two to three days. A "contact" for prescription drugs was necessary at all times. Patients may have been frustrated with other aspects of health care, but the relationship with the health care provider could not be tampered with, or severed, because otherwise the "drug connection" would also be severed. The fear of pain was too encompassing to lose a "drug contact!" A love-hate, passive-aggressive relationship thus may have resulted.

The subjects had hoped for resolution of their fears, but most had found no resolution. There was also concern about the permanent and temporary harm from the illness and therapy. But these fears were not communicated, and therefore, not allayed either.

Present Expectations

The intervention expected by the subjects was straightforward -- a "cure" was wanted. Second priority expectations included advice, insight, and "someone who would listen." Most patients had expected lab tests and x-rays. Most patient stated that much time, effort and money would be given to have received a "cure." One-half of the patients felt that the practitioner and the patient should have shared equal responsibility for a "cure." One-third of the subjects wanted the practitioner to have shouldered the whole responsibility.

Limitations of Study

The patients did not have enough insight into beliefs and illness behaviors to fully mirror the patient explanatory model. The patients had difficulty expressing ideas and feelings.

This group of subjects was used to "paying others" to intervene and solve past problems. These patients had not assumed responsibility for the chronic illness.

Recommendations for Future Research

The following recommendations for future research are made:

1. The use of non-M.D. practitioners by patients with chronic headaches needs to be investigated more

fully. Why are these practitioners seen as more "approachable?" Are they more available to the subjects? What is the cost difference in clinic visits versus M.D.s? Is there a different time allotment per patient? What is the educational background of these practitioners? How do these practitioners view chronic headaches? What mechanism of pain is involved? What expectations and goals do these practitioners have? Are short-term or long-term goals set? Do these practitioners have set programs of therapy or are individual programs set up for each patient? If so, what basis is used to set up these programs?

2. Patients' definitions of the specialists' roles needs to be explored. Studies should have patients describe the function and role of medical doctors from general practitioners to specialists. How does the patient see the consulting and referral roles? The patient should be able to list expectations of the M.D., including expected results. The patient should define any discomfort in communicating questions or feelings, or in expecting results. What are the barriers in communication that the patient perceives? Can the patient see any resolution to those barriers?

It would also be useful to query the medical doctors on similar questions in order that they might

provide the physician perspective.

3. Self-directed interventions need to be surveyed more fully. A lot of "folk medicine" and "family remedies" still need to be investigated. The populations that should be surveyed are those groups not seeking or requiring formal health care intervention.

4. More research needs to be set up using the patient explanatory model or other anthropological models of history-taking in evaluating not only chronic headaches, but other chronic and acute illnesses.

This same patient explanatory model could be used in repeat studies on similar or different populations.

By more research studies, better histories mirroring the true patient could be expanded and established as part of medical history taking.

Significance to Nursing

Chronic headache is a repeating behavioral illness requiring diligent intervention. The practitioner must act as an integrator for all aspects of the illness -- not as the person who will "cure the disease."

Since "structural disease" is not present, practitioners may want to dismiss the patient as being credible. "When (practitioners) dismiss illness because ascertainable "disease" is absent, they fail to meet so-

cially assigned responsibility" (Eisenberg, 1977, p. 8). Remember that the patient still has "dis-ease."

Chronic headaches require long, ongoing, follow-up therapy with occasional crisis involvement. If it is ever necessary to refer a patient for neurological consultation, the decision must be made as to which practitioner will assume total ongoing care for the patient. The practitioner assuming care must be available for ongoing and emergency appointments. Along with the chronic headaches, the beliefs, behaviors and attitudes must also be managed.

The best course of action would be for the primary care practitioner to be the one to assume total care of the patient. If neurological, or other specialist consultation is ever indicated (for example, positive neurological findings, change in nature of headache, new associated symptoms, unexplained increase in frequency, duration, or occurrence of headaches, or head pain usually associated with hemorrhages, aneurysms, infections and so on), then detailed explanation must be made for the patient outlining the specialist's role of consultation. Leave the type of x-rays and tests up to the specialist. If a certain test or examination is particularly important for the work-up, then give an explanation to the specialist why this test is desirable. Ex-

pect written communication (at least) from the specialist regarding findings, outline of therapy, and suggested follow-up. The specialist's role is simply to help in defining a specific modality treatment for the patient. But first, the primary care provider must develop a trusting relationship built over several appointments. Using the patient explanatory model, the patient's past medical history, personal beliefs, previously tried self-directed interventions, past experiences with both non-M.D. and medical practitioners, and present expectations can be outlined. The patient becomes a therapeutic ally for treatment and goals. The practitioner will slowly be giving back the locus of control to the patient. The responsibility for the disease will be given back to its owner. The practitioner will then be seen as just an occasionally necessary guide who will give support when needed.

Through beginning therapy, a few thoughts need to be kept in mind. a) These patients are not self-directed, and have never used the concept of cause and effect to any great extent. Education is needed to develop insight and to learn cause and effect relationships. b) These patients have developed a helplessness/hopelessness ideation. No help has been found before, therefore the situation must be hopeless. c) The big-

gest fear that these patients experience is the pain itself. This must be brought out and openly talked about. A thorough physical exam with neurological components is indicated during the course of appointments. Baseline CBC, chemistry survey and urinalysis should be done. However, other testing and x-rays should only be done if the history and physical warrant further testing.

While moving through the first few appointments, the patient should be filling out a daily journal of feelings, headache experiences, and possible trigger factors, hence initiating the cause and effect awareness. The patient should also write down meals, activities and sleep patterns. These journals are then brought into each appointment for discussion and future entries. Bases for types of treatment can be determined by the patient's activities of daily living. Using the journal together, appropriate times for therapy modalities can be worked out.

Pain management techniques should be implemented from the first visit. Relaxation techniques, slow stretching range-of-motion exercises of the neck and shoulders, proper use of heat and ice, and gentle massage are new ways for the patient to begin controlling the pain. These techniques are reemphasized at all subsequent visits. Have the patient perform or describe

the techniques during the clinic visit. Then corrections can be made, if necessary, and possibly further techniques can be added such as isometric neck and shoulder exercises, or slow beginning aerobics such as slow walking. Aerobics that result in a rapid pulse, increased blood pressure, and "jarring sensation" to the head may only exacerbate existing headaches. When the head pain is under control, then further aerobic exercises can be added.

Use of medications should be seen as an adjunct to therapy, not as "cure" in itself. Instead of prescribing the "usual headache" narcotic pills, use of tricyclic antidepressants such as amitryptilline, in slowly increasing doses up to 75-100 mg each night, is recommended. Nonsteroidal anti-inflammatories are a good medication for relieving soreness and inflammation of the head and neck structures. Using both the input of the practitioner and the patient, set short and long-term goals for the patient. At subsequent appointments, then determine any needed changes in treatment modalities. Counseling will always be necessary to call attention to behaviors that have maintained the chronic headache in the past. At times, a psychologist or psychiatrist may be needed for intervention.

The patient needs the explanation that chronic

behaviors are making it impossible to break out of the chronic headache cycle. These behaviors can best be searched out by a psychologist or psychiatrist, with changes initiated in thinking in behavior. Explanation needs to be made that the practitioner is still the primary care provider, the integrator of all other professional consultation.

Categorization of the headache by current classification is probably useless. Labeling the illness as vascular or muscle contraction is an emotional issue for the patient and only closes doors to some modalities of treatment. Rather, the headache should be classified as "responsive to certain modes of treatment." For example, certain chronic headaches may be relieved by ice treatments, isometric exercise and tricyclic antidepressants. Others may respond best to anti-inflammatories, daily beta-blockers, or decongestants. The practitioner is then treating the patient and headache more realistically.

After initial modalities of therapy are controlling the pain, and behavior is being examined, the practitioner should look into general health maintenance with the patient. The patient will then develop more control over all activities of daily living including diet and overall exercise. The patient should no longer be envi-

sioned as a chronic headache patient, but as a healthy patient with controlled headaches.

Chronic headaches are a very difficult illness to treat. They are well within the scope of the role of the family practitioner or nurse clinician, but are exasperating for both practitioner and patient most of the time. A solution may not always be found, but it is "worth a go."

APPENDIX A

LIST OF QUESTIONS USED TO ELICIT THE PATIENT EXPLANATORY MODEL

The wording of questions will vary with characteristics of the patient, the problem and the setting; but the following questions can be used to elicit the patient explanatory model (Kleinman, 1978):

1. What do you think caused your problem?

2. Why do you think it started when it did?

3. What do you think your sickness does to you? How does it work?

4. How severe is your sickness? Will it have a short or long course?

5. What kind of treatment do you think you should receive?

6. What are the most important results you hope to receive from your treatment?

7. What are the chief problems your sickness has caused for you?

8. What do you fear most about your sickness?

APPENDIX B

INFORMED CONSENT FORM

This is a study of coping mechanisms and illness beliefs of patients with chronic headaches. The results of this study will help to develop a more comprehensive assessment of the patient with chronic headaches, thereby providing a more complete base for a therapeutic plan of care for better control and/or relief of the chronic headache.

Participation in this study involves a brief 30-minute interview with the nurse researcher. The participant in the study will be asked questions about his headaches, ways he has treated the headaches before, results of those treatments, and any ways that the headaches may have possibly interfered in the patient's life. The interview will be in addition to, and separate from, the medical appointment and physician visit.

I understand that participation in this interview may benefit me by helping me gain insight into my illness and coping behaviors.

This study will potentially benefit others, in that if we can develop a more comprehensive view of the patient and his illness, we can devise a better, more completely integrated, assessment and treatment for alleviating chronic headaches.

I understand that no information will be obtained from my medical records for use in this study.

I understand that my participation as a subject is entirely voluntary. I may ask questions about my participation at any time. Any information that I give will be coded to guarantee complete anonymity and confidentiality.

Nobody in any way has forced me to cooperate and I understand that I may withdraw my consent and terminate my participation at any time during the study without jeopardizing my medical care now or in the future.

For any questions about the research, your rights, possible termination from the project, or any other related matters, please contact Helen Eschenbacher, 268-8046, or 571-5411.

I understand that I may obtain results of the study when available upon request.

I wish to give my cooperation as a subject.

_____

Signature of participant

_____

Date

_____

Signature of witness

_____

Date

APPENDIX C

INTERVIEW FORM

Part 1

Demographic Data

Agency: Date:

Age:

Sex:

Years of formal education:

Marital status:

Income: Year_____ Month_____ Hour_____

Size of family: Children_____
Brothers_____
Sisters _____

Years lived in Utah: Urban_____
Rural_____

or elsewhere:

Generations of family in Utah:

elsewhere:

Race or ethnic origin:

_____ Asian American/Oriental

_____ Black/Negro

_____ Caucasian

_____ Native American/American Indian

_____ Spanish surnamed American

_____ Refuse to indicate

_____ All others

Part 2

Nature of Headache

1. Describe your headache.

   Character of pain: throbbing, sharp? dull? band-like? Pressure?

   Onset: When did headaches first start in your life? Is onset slow-building or sudden? What time of day do the headaches start?

   Location:

   Duration: How long does each headache last?

   Occurrence: How often do you get headaches? Do they ever completely go away?

   Exacerbation: What makes the headache worse? (exercise, smoking etc.) Does the headache get worse or better as the day progresses?

   Associated Symptoms: What other symptoms do you have with your headache? Vertigo? Chills? Swelling? Tremor? Abdominal pain? Mood disturbances? Diarrhea? Polyuria? Weakness? Photophobia? Nausea? Vomiting?

   When do you get these other symptoms in the course of your headaches?

   Do you ever have a warning (prodrome) that you are getting a headache? Scotoma? Diplopia? Hemianopia? Gastric disturbances? Paresthesias?

   Relief: What makes the headache better? (Lying down? Eating? etc.?)

2. Who else in your family has chronic headaches? Are they like yours?

Personal Beliefs About Headaches

1. What do you think causes your headaches? Explain further about the mechanism.

2. Why do you think the headaches started when they did?

3. How severe are your headaches? (Rate them on a scale of one to 100, if 100 were the worst pain that you ever experienced, and one were no pain at all).

4. Will these headaches be something that will always be with you or is it something that will stop someday? Why?

5. Do you think that your headaches harm you in any way? Permanently? Temporarily? How?

6. Do you have any fears at all about your headaches?

7. If you do, what do you fear most about your headaches?

8. What are the chief problems that your headaches have caused for you?

a. Activities of daily living
b. Social interactions
c. Work or working relationships
d. Family relationships
e. Recreation
f. Self-concept or esteem

Experiences with Own Coping Mechanisms

1. What treatment have you done for yourself in the past or present for headache relief?

2. Where did you get the information for treatment? Magazines, books, friends, co-workers, family, neighbors, TV, radio, others?

3. What specific treatments have your tried? (for example, medicines, herbs, heat or cold, physical therapy, etc.)

4. When do you first start treating your headaches? (First warnings? First pain or discomfort? With increased pain? With associated symptoms?)

5. What results do you have with these treatments?

6. Did you ever receive treatment or advice for your headaches from:

   a. chiropracters
   b. herbalists
   c. osteopaths
   d. naturopaths
   e. others

7. What specific treatment did you receive? What results did you have? Would you return to any of these practitioners again for headaches or other illnesses?

8. What was your general satisfaction with these kinds of treatment?

9. Would you return to any of these practitioners?

Experience with the Health Care or Medical System

1. What doctors or nurses have you seen for your headaches? When?

2. What advice and/or treatment did you receive?

   a. drugs-type?
   b. psychotherapy/counseling
   c. change in lifestyle
   d. change in diet
   e. biofeedback
   f. pain clinic
   g. physical therapy
   h. surgery
   i. other

3. What were the results?

4. Has anyone ever told you that you had a certain type of headache (e.g., migraine, cluster, tension, etc.?).

5. What was your general feeling or satisfaction with the medical system?

6. Were your fears resolved?

Present Expectations

1. Who was responsible for making the appointment with the neurologist?

2. What kinds of treatment or service did you think that you should receive?

a. tests
b. x-rays or scans
c. prescriptions
d. advice
e. insight into illness
f. someone who will listen to problem
g. cure for the headache

3. What were the most important results you hoped to receive from your treatment?

4. How much time, and energy are you willing to give up to help stop your headaches? Do you think that the physician or practitioner should have most of the cure or help for your headache?

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